RESEARCH SUBJECT CONSENT FORM

Title:	Patient Experience and Treatment Preferences of ATTR Patients and their Caregivers
Protocol No.:	ARC004
Sponsor:	Amyloidosis Research Consortium
Investigator:	Sabrina Rebello 320 Nevada Street, Suite 210 Newton, MA 02460 United States
Study-Related Phone Number(s):	617-467-5170

DETAILED RESEARCH CONSENT

You are being invited to take part in a research study. A person who takes part in a research study is called a research participant.

What should I know about this research?

- This form explains this research to you.
- Taking part in this research is voluntary. Whether you take part is up to you.
- You can choose not to take part. There will be no penalty or loss of benefits to which you are otherwise entitled.
- You can agree to take part and later change your mind. There will be no penalty or loss of benefits to which you are otherwise entitled.
- If you don't understand, ask questions.
- Ask all the questions you want before you decide.

Why is this research being done?

The purpose of this research is to increase the understanding of the burden of ATTR on patients and their caregivers and the results will be used to inform the Amyloidosis Forum on the burden and unmet need of patients and caregivers with ATTR. The survey is intended to generate data that will help the community understand the how the burden has changed in the past five years now that four treatments are available.

Who and how many people are being asked to participate in this research?

Individuals or caregivers of individuals with ATTR amyloidosis are invited to take part in this research. About 500 participants will take part in this research.

How long will I be in this research?

We expect that your taking part in this research will last 30 minutes.

What happens to me if I agree to take part in this research?

This research relies on an online survey that does not collect personally identifiable information. Therefore, your participation is limited to answering the survey questions online and you will not have direct contact with the research team.

The survey consists of approximately 60 questions. There are unique surveys for patients and caregivers to complete. While you can leave in the middle of the survey and return to the same page you left off, we encourage completing the survey in one sitting.

Data collected via this one-time online survey will be aggregated and analyzed by the research team at ARC. Quotes from the text fields may be used in reporting but will not be attributed to you. You may choose not to provide any quotes. The report and manuscript that will summarize the results of this study will report only aggregate numbers and is slated to be completed by the December 2023. Once published, study findings will be available at arci.org.

What are my responsibilities if I take part in this research?

If you take part in this research, you will be responsible to answer the one-time online survey. There will be no follow-up survey or additional responsibilities. You will not be contacted or asked to provide any additional information.

Could being in this research hurt me?

Participation in an online survey is voluntary and has minimal risk to you. It does not include physical risks, legal risks, social risks, or economic risks. However, you may experience discomfort answering questions about experiences you or your family have related to amyloidosis, which may be associated with psychologic risks (such as embarrassment).

Your answers are confidential and no personally identifiable information is asked. The datasets that will be downloaded from the online survey vendor's website will be stored in a password-protected manner that only the research team will have access to. Privacy risks, such as disclosure of private information is not possible as it is not collected.

Will it cost me money to take part in this research?

Taking part in this research may lead to added costs to you, such as: costs of internet access or a device to access the internet.

Will being in this research benefit me?

There are no benefits to you from your taking part in this research. We cannot promise any benefits to others from your taking part in this research. However, possible benefits to others include learning more about what the burden of disease is on patients and their caregivers and identifying any unmet need.

What other choices do I have besides taking part in this research?

This research is not designed to diagnose, treat or prevent any disease. Your alternative is to not take part in the research.

What happens to the information collected for this research?

This research does not collect information such as your private personally identifiable information (such as name, email address, etc.) or your medical records. Your private

information (your answers to the survey questions) will be shared with individuals and organizations that conduct or watch over this research, including:

- The research sponsor
- People who work with the research sponsor
- Government agencies, such as the Food and Drug Administration
- North Star Review Board, Institutional Review Board (IRB) that reviewed this research

We may publish the results of this research. However, data will be aggregated, and no individual data will not be singled out. The aggregated reporting ensures your survey responses are confidential.

We protect your information from disclosure to others to the extent required by law. We cannot promise complete secrecy.

The deidentified data collected in this research might be used for future research or distributed to another investigator for future research without your consent.

Who can answer my questions about this research?

If you have questions, concerns, or complaints, or think this research has hurt you or made you sick, talk to the research team at the phone number listed above on the first page.

What if I am injured because of taking part in this research?

There is no risk of injury or sickness because of taking part in this research.

Can I be removed from this research without my approval?

The person in charge of this research can remove you from this research without your approval. Possible reasons for removal include: not completing the entire survey, or answers you provide which are outside a reasonable range or highly improbable. To limit the possibility of out of reasonable range responses, the survey has some logical validation rules in place. For example, in a question asking in the past 30 days, how many days have you experienced an event; only a response between 0-30 will accepted. A vast majority of questions are multiple choice and this minimizes the risk of removal from the research.

What happens if I agree to be in this research, but I change my mind later?

If you decide to leave the research early by exiting the survey before the last question, there are no risks with this decision. Any responses you answered prior to leaving the survey may be used as part of the aggregated data. No contact or notification to the research team is required.

Will I be paid for taking part in this research?

You will not be paid for taking part in this research.

Statement of Consent:

By clicking on the survey link and continuing to the online survey, you provide your consent to participate in this study.